Development and psychometric properties of the Carer - Head Injury Neurobehavioral Assessment Scale (C-HINAS) and the Carer - Head Injury Participation Scale (C-HIPS)

Development and psychometric properties of the Carer – Head Injury Neurobehavioral Assessment Scale (C-HINAS) and the Carer – Head Injury Participation Scale (C-HIPS): patient and family determined outcome scales

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Objective: Develop and assess the psychometric properties of the Carer – Head Injury Participation Scale (C-HIPS) and its biggest factor the Carer – Head Injury Neurobehavioral Assessment Scale (C-HINAS). Furthermore, the aim was to examine the inter-informant reliability by comparing the self reports of individuals with traumatic brain injury (TBI) with the carer reports on the C-HIPS and the C-HINAS.

Method: Thirty-two TBI individuals and 27 carers took part in in-depth qualitative interviews exploring the consequences of the TBI. Interview transcripts were analysed and key themes and concepts were used to construct a 49-item and 58-item patient (Patient – Head Injury Participation Scale [P-HIPS]) and carer outcome measure (C-HIPS) respectively, of which 49 were parallel items and nine additional items were used to assess carer burden. Postal versions of the P-HIPS, C-HIPS, Mayo Portland Adaptability Inventory-3 (MPAI-3), and the Glasgow Outcome Scale-Extended (GOSE) were completed by a cohort of 113 TBI individuals and 80 carers. Data from a sub-group of 66 patient/carer pairs were used to compare inter-informant reliability between the P-HIPS and the C-HIPS, and the P-HINAS and the C-HINAS respectively.

Results: All individual 49 items of the C-HIPS and their total score showed good test-retest reliability (0.95) and internal consistency (0.95). Comparisons with the MPAI-3 and GOSE found a good correlation with the MPAI-3 (0.7) and a moderate negative correlation with the GOSE (–0.6). Factor analysis of these items extracted a 4-factor structure which represented the domains 'Emotion/Behavior' (C-HINAS), 'Independence/Community Living', 'Cognition', and 'Physical'. The C-HINAS showed good internal consistency (0.92), test-retest reliability (0.93), and concurrent validity with one MPAI subscale (0.7). Assessment of inter-informant reliability revealed good correspondence between the reports of the patients and the carers for both the C-HIPS (0.83) and the C-HINAS (0.82).

Conclusion: Both the C-HINAS and the C-HIPS show strong psychometric properties. The qualitative methodology employed in the construction stage of the questionnaires provided good evidence of face and content validity. Comparisons between the P-HIPS and the C-HIPS, and the P-HINAS and the C-HINAS indicated high levels of agreement suggesting that in situations where the patient is unable to provide self-reports, information provided by the carer could be used.

Keywords: traumatic brain injury, neurobehavioral outcome measure, C-HIPS, C-HINAS, psychometrics

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Introduction

Despite recent medical advances a large number of patients with traumatic brain injury (TBI) continue to suffer from long term consequences (Moscato et al 1994). There have been many longitudinal studies of TBI patients (see recent studies: Levin

et al 1990; Cifu et al 1997; Hellawell et al 1999; Kersel et al 2001; Novack et al 2001). TBI can cause lasting physical and mental difficulties (Deb et al 1998, 1999a, 1999b; Thornhill et al 2000) often with hidden psychological, cognitive, and behavioral problems (Deb et al 1999a; Stilwell et al 1999). These problems can have a serious impact on the quality of life not only of the TBI individuals but also of their families (Oddy et al 1978; Brooks et al 1986; Prigatano and Schacter 1991). Although initial severity of brain injury is an important prognostic factor for the long term outcome, many recent studies have highlighted the influence of psychosocial and many demographic variables on the outcome of the TBI (Chiang et al 2003; Kreutzer et al 2003; Franulic et al 2004; Slewa-Younan et al 2004; Wilde et al 2004).

The influence of cognitive factors in the overall functional outcome following the TBI has been emphasized in recent studies by Rassovsky and colleagues (2006a, 2006b). The authors found that neurocognitive deficits showed a stronger association with functional outcome than emotional and behavioral difficulties among 87 patients with moderate to severe TBI (Rassovsky et al 2006a). Within the neurocognitive deficits and frontal lobe deficits, particularly manifested through impaired speed of information processing, was a more important prognostic factor for social and occupational functioning than verbal memory problem for example (Rassovsky et al 2006b). Similarly, the role of emotional adjustment as a coping strategy to improve psychosocial rehabilitation following the TBI was emphasized in a recent study by Anson and Ponsford (2006).

Despite the prominence of behavioral and emotional problems in the post-acute stage of the TBI, proper assessment scales for these domains in the post-acute stage are lacking. The neurobehavioral scale devised by Levin and colleagues (1987) has been validated among TBI individuals but does not distinguish between psychiatric symptoms such as hallucinations and delusions and neurobehavioral symptoms such as lack of motivation. Similarly, the neuropsychiatric inventory (NPI) (Cummings et al 1994), which is designed for patients with neurodegenerative disorders, also combines items of psychiatric symptoms with behavioral and emotional symptoms. Delusions and hallucinations can arise from a brain injury but they could also be the manifestation of a psychiatric disorder which may be associated with the brain injury at all ages (Deb and Burns 2007). It is therefore necessary to carry out a full psychiatric diagnostic assessment of the brain-injured patients in order to differentiate between the two because the treatment will depend on the exact cause of these symptoms. Also both these scales measure symptoms but not the level of handicap which is a more relevant measure of outcome at the post acute stage of rehabilitation.

Previous measures have not addressed the specific subjective experiences of the TBI individuals and their families. Studies reporting on the correspondence between the patient and the carer reports have found that there are discrepancies between self and other reports. Teasdale and colleagues (1997) found that, when administering the European Brain Injury Questionnaire (EBIQ), carers generally reported greater problems particularly when the items related to attitudes and behaviors. This was in comparison to self and other reports of a nonbrain-injured control group, who revealed no such pattern of differences (Teasdale et al 1997). On the other hand, carers may not be able to report on the inner emotional feelings of the patients; therefore both patient and carer reporting will be desirable for a holistic assessment.

Outcome measurement is essential for identifying areas of difficulty, planning interventions, and assessing the effectiveness of rehabilitation programmes (Ponsford et al 1999), and establishing sound psychometric properties of any instrument is essential to the potential utility in clinical or research practice (Wade 1998). There are a number of measures which are used to assess outcome in TBI, but few are considered to be fully established or validated for measuring post-acute outcome (Stilwell et al 1999; Fleminger and Powell 1999). The psychometric properties of many of the existing scales are poor or have not been properly assessed (Hart and Hayden 1986; Hall 1992; Lezak 1993; Wade 1998).

The World Health Organization (WHO)'s International Classification of Impairments, Disabilities, and Handicaps (ICIDH) model (WHO 1980, 1997) provides an important framework for the development of post-acute measures in TBI. The terms 'disabilities' and 'handicaps' are now referred to as 'activities' and 'participation' respectively (WHO 1997, 2001). Most outcome measures tend to focus on measuring disability and impairment, as they are perceived as easier concepts to define and measure in comparison with the concept of participation (Cardol et al 1999). Participation focuses more on the difficulties that an individual encounters in relation to their social context following from their injury (Wade 1998) and concentrates more on the individual's own perspective of their injury. In post-acute rehabilitation, the recovery or change of the individual is slower and less dramatic, and thus outcome measures which have been developed for acute settings are often insensitive to gradual change (Kilgore 1995), due to their apparent ceiling effects (Fleminger and Powell 1999). The main focus of rehabilitation at this stage is upon the individual's psychosocial adjustment, specifically reduc-

ing obstacles to community reintegration due to behavioral, emotional, and cognitive difficulties (Malec et al 2000).

Despite the existence of a plethora of outcome measures following TBI, it has been argued that there is a lack of established or well validated instruments to measure post-acute outcome in this population (Stilwell et al 1999; Fleminger and Powell 1999). The psychometric properties of many of the existing scales are poor or have not been properly assessed (Hart and Hayden 1986; Hall 1992; Lezak 1993; Wade 1998). At present most available outcome measures used in this population are devised by professionals with little or no input from the TBI individuals and their families. One notable exception is the Neurobehavioral Functioning Inventory (NFI) (Kreutzer et al 1996). Although the authors used patient and carer interviews along with other methods for gathering information for the questionnaire items, it is unlikely that they analyzed interview data using a structured standardized method of qualitative data analysis.

Therefore, the aim of the current study was to develop a post-acute outcome measure with items generated from the TBI individuals' and their families' own accounts of the consequences of the TBI with particular emphasis on producing a neurobehavioral scale. The reasons for developing our scale are: (a) there are not many scales available that could be used to assess progress at the post-acute stage of recovery from the TBI; (b) most existing scales measure symptoms rather than the level of participation; (c) most existing scales are devised by professionals with minimum input from patients and their carers; (d) as far as we know no scale used structured and standardized qualitative method of analysis of patient and carer interview data in order to develop questionnaire items; (e) most existing scales for use at the post-acute stage either do not report on their full psychometric properties or do not have good psychometric properties or recruited an inadequate number of patients to assess their psychometric properties (see discussion section); (f) most post-acute scales do not emphasize the neurobehavioral outcome following the TBI; and (g) most scales either do not have parallel versions for use by the patients and the carers or even if they do, they do not provide adequate good quality psychometric data on the comparison between the patient and the carer reporting (see discussion section).

Method

The questionnaire was devised according to the following guidelines proposed by the UK Medical Research Council: (a) a questionnaire should be simple to use, (b) should not take long to complete, (c) could be re-usable in different settings, (d) could be completed by a proxy respondent, (e) sensitive and specific to the condition for which used, (f) valid, and (g) reliable (see www.mrc.ac.uk).

The first phase of this study involved carrying out in-depth interviews with adults with TBI and their relatives and then analyzing the data derived from these interviews using qualitative methods. The themes and concepts derived from the transcripts were then used to develop two parallel patient (Patient – Head Injury Participation Scale [P-HIPS]) and carer (Carer – Head Injury Participation Scale [C-HIPS]) questionnaires, which focused on measuring 'participation' (WHO 2001). The focus of the questionnaire was on how each symptom had been a problem for the individual during the past four weeks. The second phase of this study focused on the field-testing of the newly developed outcome measure in order to assess its psychometric properties. At this stage a neurobehavioral subscale was produced using a factor analysis (the Patient – Head Injury Neurobehavioral Assessment Scale [P-HINAS] and the Carer – Head Injury Neurobehavioral Assessment Scale [C-HINAS]). Further details from the qualitative stage of the study have been published elsewhere (Morris et al 2005).

Stage 1: Development of the questionnaire: Qualitative study

Using qualitative methodology we gathered information from a group of 59 individuals; 32 patients with TBI and 27 family, friends, or paid carers regarding their perceptions of consequences of the TBI. Potential interviewees were identified via TBI services in the Cardiff area, Wales, UK. Approximately 300 patient files were screened to identify individuals with probable moderate or severe disability resulting from a TBI sustained whilst aged over 16. The actual level of disability was subsequently determined using the Glasgow Outcome Scale. Purposive sampling method was used in order to get views from individuals with a mix of disability levels, gender, and age at injury. All interviews were conducted at least one year post injury and all interviewees had returned to a home environment for at least six months prior to being interviewed.

Semi-structured interviews that focused on narratives of personal experience were conducted with individuals and their carers. Interviewees were asked to describe their lives prior to the injury and then to describe the consequences of the TBI that had been most important to them. Open-ended questions were designed to collect as much information as possible on the

impacts of the injury on the lives of patients and their carers, and to identify those areas, which interviewees considered to be particularly significant. These interviews were all recorded onto minidisk and transcribed in full.

Initially, a simple concordance programme was used (a) to identify a list of the most frequent terms used in the interviews, and (b) to highlight differences of word use in patient and carer interviews. The concordance results subsequently provided the elements of a user-friendly language in terms of which the questions in the subsequent instruments could be posed, and were also suggestive of some initial themes for analysis. Following that, the full interview transcripts were repeatedly read over in combination with listening to the recorded interviews. Emergent themes reported by participants as being important in the outcome following the TBI were then coded. The coding process was akin to that described by Strauss and Corbin (1990), and was later facilitated by the use of NUDI*ST (N5) (Qualitative Solutions and Research Pty Ltd, Melbourne, Australia), a qualitative software data analysis package (Richards 2000). The coding exercise generated items for inclusion in the questionnaire.

Forty-nine identical questions were selected for the final drafts of both versions of the P-HIPS and the C-HIPS, with only slight differences in wording so that in the patient version the items refer to the self whereas, in the relative/carer version the items refer to the person they care for. The same ranking system (eg, '0' = not a problem, '1' = mild problem, '2' = moderate problem, and '3' = serious problem) has been used for all questions. The emphasis was on assessing 'participation' and thereby the impact of each symptom on the individual rather than simply rating the presence of symptoms. For example a patient may have a visual problem, but this does not cause any problem for his day to day activities because he wears spectacles. In this case the patient will report 'not a problem' in the 'difficulty with eyesight' section of the C-HIPS/P-HIPS. This approach is seen particularly important at the post-acute stage of outcome as the residual symptoms tend to plateau by that time. In the C-HIPS there are an additional nine questions concerning the effect that the TBI has had on the carers/relatives themselves, which were included to give a measure of carer burden.

Before finalizing, the two versions of the questionnaire (ie, the P-HIPS and the C-HIPS) were sent for comments to all the original sample of the TBI patients who took part in the qualitative stage of the study, their carers, and some professionals working with the TBI patients. Comments were gathered from patients and their carers on the questionnaire items, language used in the questions, layout, and color of the paper. In the light of the comments and feedback received, the draft versions of the questionnaire underwent minor revisions in content. Before finalizing the questionnaire, we checked whether participants were consistently missing any particular item or providing the same answer. We also checked for possible floor or ceiling effect from the spread of overall scores from all participants.

Stage 2: Field testing of the questionnaire: Quantitative study

Participants

The two parallel versions of the questionnaire were field-tested on a cohort of 113 TBI patients (90 males; mean age: 42 years; SD: 13 years) and carers (14 males; mean age: 52 years; SD: 11 years) of 80 of these patients. Inclusion criteria were as follows: (a) Patients must have experienced the TBI at least one year prior to taking part in the study; (b) Patients must have had the TBI whilst aged over 16; and (c) Carers must have known the individual for at least four weeks as they were reporting on the previous four-week period.

Procedure

Ethical approval for this study was granted by the West Midlands Multi-Centre Research Ethics Committee (MREC), UK. Participants were recruited from the TBI services nationwide in the UK including many neurorehabilitation units. All participants completed by post the newly developed questionnaire along with the postal version of the Glasgow Outcome Scale – Extended GOSE, (Wilson et al 2002) and the Mayo Portland Adaptability Inventory-3 (MPAI-3) (Malec et al 2000). Once these were returned, our newly developed questionnaire was sent out again immediately. Sixty-five carers sent the completed C-HIPS back twice, which helped to calculate the test retest reliability of the C-HIPS.

Results

In this paper we primarily present data related to the C-HIPS and the C-HINAS and some comparison between the C-HIPS and the P-HIPS, and the C-HINAS and the P-HINAS. The data relating to the P-HIPS and the P-HINAS are presented in a separate paper (Deb et al 2007).

Sample characteristics

Carers reported that 41% of the patients had lower severe disability according to the GOSE. Twenty-five percent had upper severe disability, 17% had lower moderate severity, 10% had upper moderate severity, 4% lower good recovery,

and 3% had upper good recovery. The three main causes of the TBI reported by participants were road traffic accidents (66.1%), falls (17.3%), and assaults (7.9%). Other reported injuries included sports injury and cycling accidents. Analysis showed that 97.5% of carers knew the individuals with TBI prior to their injury. There was a sub-group of 66 patient/carer pairs that took part in this study. These data were used to calculate the inter-informant reliability.

Factor analysis

This was done by carrying out a principal components analysis (Field 2005). Initially we included all factors with an eigenvalue ≥1 using a varimax rotation method. This was done on the C-HIPS and the P-HIPS and similar factors were detected for both. However, in order to compare the P-HIPS domains with the C-HIPS domains we have used the same P-HIPS factor structure for the C-HIPS (see Table 1). The Keiser Meyer Olkin statistic for sampling adequacy was 0.87, suggesting if factor analysis is conducted, the factors extracted will account for substantial amount of variance. Scree plot analysis identified four factors for rotation, accounting for 52.84% of the total variance (see Table 1). As shown in Table 1, Factor 1 is the biggest factor consisting of 20 items related to emotion and behavior. The items of this factor are put in a separate scale and the patient version is named as the P-HINAS and the carer version as the C-HINAS. Factor 2 is the second biggest factor consisting of 13 items relating to independence and community living (Carer – Head Injury Community Living Scale [C-HICLS]). These included preparing meals, travel, and lack of independence. Factor 3 consists of 9 cognitive items (Carer – Head Injury Cognitive Assessment Scale [C-HICAS]). Factor 4 is the smallest and consists of 7 items related to physical handicap (Carer – Head Injury Physical Assessment Scale [C-HIPAS]). The P-HINAS and the C-HINAS scales can be used on their own to assess neurobehavioral outcome following TBI or with items from other factors, particularly the cognitive factor (C-HICAS). We have found from the subsequent use of the C-HIPS/P-HIPS among our clinic patients that they and their carers found the question on sex life too sensitive to answer. Therefore, we suggest that this item should be excluded before this questionnaire is used in day to day practice.

Internal consistency

Cronbach's alpha for the total C-HIPS revealed a coefficient of 0.95 for the total score and 0.90 for the additional carer burden section. The alpha coefficients of the four C-HIPS domains are 0.92 for the C-HINAS, 0.92 for 'Independence/Community Living', 0.91 for 'Cognition', and 0.84 for 'Physical'.

Criterion-related validity – GOSE

The correlation between the C-HIPS's total scores and the GOSE category ratings was –0.61 ($p < 0.001$, $N = 77$). The GOSE category ratings spanned a wide range of scores on the C-HIPS. This is particularly marked for the first two parameters. Lower and upper good recovery scores did not show a wide range of scores. However, there were relatively small numbers of individuals in these two groups (see Figure 1).

Criterion-related validity – MPAI-3

The correlation between the C-HIPS's total scores and the MPAI-3's total scores was 0.70 ($p < 0.001$, $N = 73$). Table 2 illustrates the comparisons between the domains of the C-HIPS and those of the MPAI-3. The correlations between the domains of both questionnaires were all significant (see Table 2), however correlations above 0.69 were found between the C-HINAS and the MPAI-3 'Pain/Emotion' score ($r = 0.70$), the C-HIPS 'Independence/Community Living' scale and the MPAI-3 'Social Participation' score ($r = 0.71$). The C-HIPS 'Cognition' scale had its highest correlations with the MPAI-3 'Physical/Cognition' score ($r = 0.70$). The C-HIPS 'Physical' domain had correlated well with all three MPAI-3 domains; 'Pain/Emotion' Score ($r = 0.75$), 'Physical/Cognition' ($r = 0.72$) and 'Social Participation' score ($r = 0.76$). The MPAI-3 Total Score correlated significantly with all four domains of the C-HIPS ($r = 0.60$–0.82, $p < 0.001$).

Test re-test reliability

The C-HIPS total scores for the 49 items showed good test-retest reliability (Intraclass correlation; ICC = 0.95) ($p < 0.001$, $N = 65$), with individual item's reliability ranging from 0.65 to 0.89 ($p < 0.001$, $N = 61$–65). The test-retest reliability of the four domains were 0.93 ($p < 0.001$, $N = 65$) for the C-HINAS, 0.95 ($p < 0.001$, $N = 65$) for 'Independence/Community Living', 0.92 ($p < 0.001$, $N = 65$) for 'Cognition', and 0.93 ($p < 0.001$, $N = 65$) for 'Physical'. The ICC for the carer burden section was 0.87 ($p < 0.001$, $N = 64$) with a range of 0.48 to 0.82 ($p < 0.001$, $N = 63$–65) for individual items.

Inter-informant reliability

The ICC is 0.83 for the comparison of the total scores of the C-HIPS and the P-HIPS for the 66 patient/carer pairs that

Table 1 Factor analysis of the P-HIPS/C-HIPS

		Emotion/ Behavior (C-HINAS)	Independence/ Community Living	Cognition	Physical
	Eigenvalue	16.75	4.01	2.76	2.38
	% variance	34.18	8.18	5.63	4.85
	Cronbach's α coefficient	0.93	0.91	0.89	0.81
28	Temper/irritable	0.696			
29	Social behavior	0.665			
31	Lack of motivation	0.679			
32	Difficulty with feeling tired/fatigued	0.434			0.463
33	Difficulty with sleep	0.415			
34	Feeling scared	0.670			
35	Paranoia	0.716			
36	Feelings of loss	0.716			
37	Frustration	0.677			
38	Worrying about things	0.685			
39	Crowds	0.584			
40	Loss of confidence	0.598			
41	Depression	0.800			
42	Arguments with close family	0.649			
43	Reduced interest in family	0.442			0.470
44	Strain on family	0.495			
46	Don't see friends as often as would like	0.524			
47	Lack of good friends	0.652			
48	Lack of understanding from others	0.442			
50	Lack of people to talk to	0.588			
09	Difficulty with mobility		0.724		
10	Lack of independence		0.782		
11	Sports activities		0.675		
12	Leisure activities		0.489		
13	Preparing meals		0.696		
14	Travel		0.820		
16	Shopping		0.589		
17	Physical self-care		0.498		
18	Local environment		0.806		
23	Difficulty with balance		0.620		
24	Physical appearance		0.450		
25	Difficulty with eyesight		0.426		
45	Sex life		0.472		
02	Group conversations			0.540	
03	Difficulty reading			0.465	
04	Difficulty speaking			0.371	
05	Difficulty with recent memory			0.653	
06	Difficulty with concentration			0.737	
07	Difficulty with planning/organisation			0.693	
08	Difficulty with multi-tasking			0.580	
15	Dealing with money			0.683	
30	Safety risks			0.448	
01	Difficulty hearing				0.586
19	Difficulty with headaches				0.564
20	Pain other than headaches				0.467
21	Difficulty with epilepsy or fits				0.207
22	Difficulty with feeling dizzy/faint				0.622
26	Difficulty with buzzing noise in the ear				0.526
27	Difficulty with sensitivity to noise/light				0.715

Abbreviations: C-HIPS, Carer – Head Injury Participation Scale; P-HIPS, Patient – Head Injury Participation Scale.

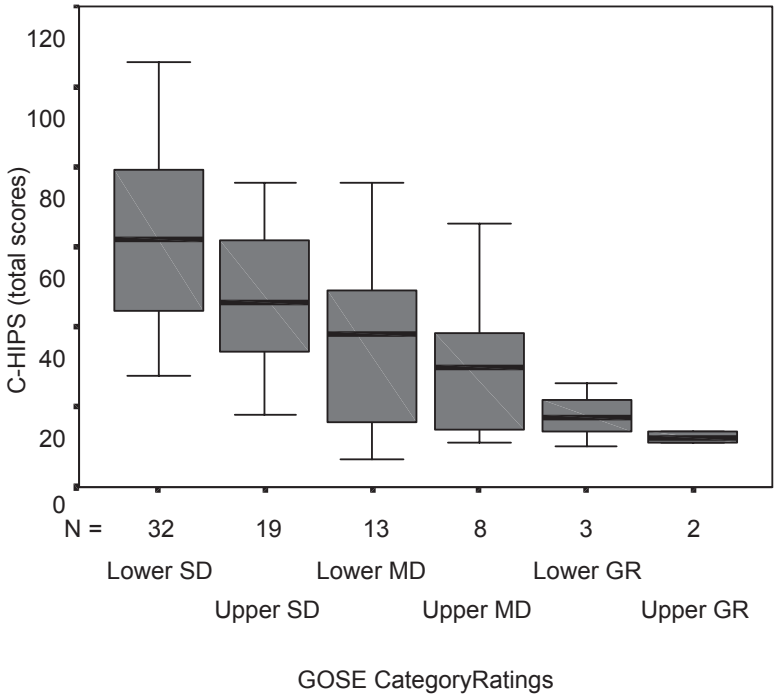

Figure 1 Comparison between the C-HIPS total scores and the GOSE category ratings.
Abbreviations: C-HIPS, Carer – Head Injury Participation Scale; GOSE, Glasgow Outcome Scale-Extended; GR, good recovery; MD, moderate disability; SD, severe disability.

took part in the study. For individual items the ICC ranged from 0.57 ('difficulty with concentration') to 0.95 ('difficulty with headaches'). The Wilcoxon signed ranks test showed significant differences in the responses of the patients and the carers in the following seven items out of the 49 common items of the patient and carer versions of the HIPS, ($p < 0.05$): (a) difficulty with planning and organization, (b) lack of independence, (c) preparing meals, (d) temper/irritable, (e) argument with close family, (f) reduced interest in family, and (g) strain on family. The ICC for the individual domains for the C-HIPS and the P-HIPS were 0.82 ($p < 0.001$) for the C-HINAS/P-HINAS, 0.86 ($p < 0.001$) for 'Independent/Community Living', 0.74 ($p < 0.001$) for 'Cognition', and 0.91 ($p < 0.001$) for 'Physical'.

Discussion

The qualitative methodology that was employed to assess the patients' and the carers' own perspectives of the consequences of TBI is believed to have elicited areas of outcome that have not previously been considered by health professionals (Morris et al 2005). Through analysis of the transcripts of the in-depth interviews the aim was to develop a new outcome measure that accurately reflected the views of patients and carers concerning what they felt were the most important

Table 2 Correlation coefficient between the C-HIPS's total and domain scores and the MPAI-3 total and domain scores

	MPAI-3			
	Physical/Cognition Score	**Pain/Emotion Score**	**Social Participation Score**	**Total Score**
C-HIPS				
Emotional / Physical	0.36	0.70	0.60	0.60
(C-HINAS)				
Independence / Community Living	0.66	0.44	0.71	0.70
Cognition	0.70	0.67	0.63	0.73
Physical	0.72	0.75	0.76	0.82
Total Score	0.60	0.60	0.72	0.70

Notes: All correlations significant at <0.001 level (2-tailed).
Abbreviations: C-HIPS, Carer – Head Injury Participation Scale; C-HINAS, Carer – Head Injury Neurobehavioral Scale; MPAI-3, Mayo Portland Adaptability Inventory-3.

consequences of the TBI. It is thought that this method of development, which has not been conducted before for TBI measures, should ensure that the questionnaire has good content and face validity. During the development of the scale the importance of emotional and behavioral consequences of TBI to the patients and their carers became obvious, yet these very areas are often neglected by clinicians and service providers while planning for the long term rehabilitation of these patients. The C-HIPS and the C-HINAS were constructed to measure 'participation' as defined by the WHO's International Classification of Functioning, Disability, and Health (ICF) (WHO 2001).

Kreutzer and colleagues (1996) reported validation data on their NFI. Although 72 items included in this scale have similarities with items in the C-HIPS, the authors did not describe in detail how they developed the questionnaire. They stated that the items were taken from a bigger scale, the General Health and History Questionnaire (GHHQ) and the items were originally formulated and compiled from interviews with patients with brain injury and family members, and from thorough reviews of the brain injury literature. However, it is unlikely that they have used same rigor and qualitative methodology like ours to analyze data collected from interviews with patients and carers. Kreutzer and colleagues (1996) also had to exclude 35 of the original 105 items from the final version of the NFI as they did not meet strong statistical criteria for inclusion in the scale; nevertheless the authors thought many of these items were clinically important. In their validation study (Kreutzer et al 1996) the authors did not provide any data on reliability of the NFI, which is an important aspect of psychometric properties of any scale. The authors have compared the NFI scores with a personality scale such as the Minnesota Multiple Personality Inventory (MMPI) (Greene 1991) score but not with any standardized neurobehavioral outcome measure such as the one produced by Levin and colleagues (1987). However, in subsequent studies the authors have compared the NFI (Johnston et al 2006) with functional measures such as Functional Independence Measure (FIM) (Hall et al 1993). The same group also compared the depression subscale scores of the NFI with a clinical diagnosis of depression according to the DSM-IV (APA 1994) criteria (Kennedy et al 2005) and the Beck Depression Inventory (BDI) (Beck et al 1988) scores (Seel and Kreutzer 2003) among 172 outpatient clinic attendants with TBI.

In the past, measuring the patient's own perspective of their injury has been criticized due to lack of insight and memory problems that are commonly experienced by individuals with TBI, and therefore proxy reports were deemed as more accurate and reliable (Teasdale et al 1997). However, it is argued that carers will not be able to report patient's inner feelings and may interpret patient's behavior using their own explanations which may be different from patient's own interpretation of events. The reports of carers may also be biased by their emotional status, the severity of patient's problems, and the familiarity with the patient (Kreutzer et al 1996). The carers, however, are likely to report certain behaviors such as aggression more frequently than the patients themselves.

Comparisons between the reports of the 66 patient/carer pairs indicate that there is generally high agreement between self- and other-reports. The overall ICC for the total score is good. This is similar to the ICC reported for the Brain Injury Community Rehabilitation Outcome Scale (BICRO-39) (Powell et al 1998) and also the Community Integration Questionnaire (CIQ) (Sander et al 1997) where the agreement between patients and carers was also investigated. For the CIQ moderate to very good agreement was found for all 15 items. Although the inter-rater reliability of the Disability Rating Scale (DRS) (Rappaport et al 1982) has been investigated, no study has assessed patient-proxy agreement. Similarly, to date no studies have investigated the patient/ proxy agreement of the Community Outcome Scale (COS) (Stilwell et al 1998). Although FIM and Functional Assessment Measure (FAM) showed good inter-informant reliability (ICC: 0.85 for FIM and 0.83 for FAM) (Hall et al 1993), they show ceiling effects when used at the end of rehabilitation (Beckers et al 1999) and one year post-injury (Wilson et al 2002). No data are available on FIM/FAM's predictive value. In the current study, significant differences were found between the reports of the patients and the carers on seven items in the HIPS. In line with previous research into this area, it is the carers who are reporting the greatest difficulties in day-to-day life for these items and most of these 7 items potentially have a greater impact on the family carers than the patients themselves. Comparing our results with those of the 63-item EBIQ (Teasdale et al 1997), the authors reported 42 significant differences between patients and carers, with most of these showing over-reporting from the cares. Comparatively, the results of the current study have demonstrated that although there are differences in the patient and carer reports for the core 49 items of the HIPS these are less than in the EBIQ. These high levels of agreement indicate that in situations where the patient is unable to self-report, using a proxy informant would be useful.

The C-HIPS was compared with the MPAI-3 and GOSE to establish its criterion-related validity. There is no accepted 'gold standard' in this area; therefore two instruments were selected that were deemed to be most appropriate for the purposes of this investigation. Comparisons with the MPAI-3 revealed a good correlation for the carer total scores, which was slightly lower than the P-HIPS's total score correlations with the MPAI-3 (0.87) (see Deb et al 2007). This illustrates the trend for carers to report similar levels of problems on both scores, however this does not show that the two scales are similar in their 'item content', factor structure and effectiveness to measure change in outcome. The good correlation between the C-HINAS and the MPAI-3 'Emotion' subscale suggests similar trends for these two domains. The correlations among the other domains of the C-HIPS and those of MPAI-3 are in the right direction as well.

Compared with the MPAI-3, a lower but negative correlation with the GOSE was expected, which can be explained largely due to its broad categorical nature in comparison with the newly developed C-HIPS. Investigating how each GOSE category rating compared against total scores, it was possible to see that there was a large variation of scores particularly with the 'Lower SD', 'Upper SD', and 'Lower MD' categories which also had the highest group numbers (see Figure 1).

Cronbach's alpha for the total and domain scores of the C-HIPS including the C-HINAS were found to be high, with all coefficients above 0.8. This indicates that these questionnaires have good internal consistency. The results further demonstrate that the test-retest reliability of the C-HIPS's total scores and domain scores including the C-HINAS are good (all >0.87). The results are broadly comparable with the test-retest coefficients for the domain and total scores for the CIQ (all >0.83) (Willer et al 1993) when it was administered to 16 patients with TBI. However, this is a relatively low cohort number for the assessment of test-retest reliability. The DRS showed a test-retest coefficient of 0.95 when raters assessed 40 patients with TBI (Gouvier et al 1987). However, 3 other TBI specific outcome measures, namely GOSE (Wilson et al 2002), The Rivermead Head Injury Follow Up Questionnaire (RHFUQ) (Crawford et al 1996) and the COS (Stilwell et al 1998) do not provide any information on their test-retest reliability properties. Similarly the BICRO-39 was validated using a small cohort size of 33 (Powell et al 1998). There are no data available on EBIQ's concurrent validity and test retest reliability (Teasdale et al 1997). The test retest reliability of the total score and individual items according to the C-HIPS and the C-HINAS are between good and very good.

Conclusion

The types of reliability and validity investigated here have demonstrated that the C-HIPS and the C-HINAS have strong psychometric properties, and builds upon the results of the P-HIPS and the P-HINAS (Deb et al 2007). The sensitivity of this instrument to detect change following from a 'real world' intervention needs examination in the future, as these are essential to its potential clinical utility (Riemsma et al 2001). It is thus believed that this outcome measure will be of value in clinical practice assessing how the items covered in the questionnaire affect TBI individuals in their day-to-day life, with a particular emphasis on the neurobehavioral outcome both from a patient and carer perspective.

We made sure that the cohort represented participants with all levels of severity of outcome and all ages and different causes of TBI. Although the C-HIPS and the C-HINAS will be useful in day to day assessment of outcome of TBI patients, it is worth pointing out here that an accurate impression of consequences of brain injury requires blending information collected from several sources (Campbell and Fiske 1959). These include data from various tests, outcome scales, direct observation combined with patient and carer interviews, and patient examination (Hartlage et al 1987).

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Carer – Head Injury Participation Scale (C-HIPS)

Name of the patient:

Patient's date of birth:

Name of the carer completing the C-HIPS:

The relation of the carer with the patient:

Carer's date of birth:

Place where the scale was administered:

Name of the person administering the scale:

The role of the person administering the scale:

Date of completion:

The cause of brain injury:

The date of brain injury:

The initial severity of brain injury (eg, length of coma, PTA, or the lowest GCS score):

Current treatments:

Carer – Head Injury Participation Scale (C-HIPS)

We are interested in the things that cause problems in day-to-day life for individuals who have suffered brain injury.

Each question asks whether a particular symptom has been either 'not a problem', or a 'mild', 'moderate' or 'serious' problem in the day-to-day life of the person you care for during the past four weeks.

There are 56 questions in total and they all follow the same format. The first 48 questions ask about problems experienced by the brain-injured person you care for during the past four weeks. The last 8 questions ask about how the consequences have affected you.

Example Question

One question asks whether the hearing of the person you care for has caused her/ him problems over the last four weeks.

	Not a Problem	Mild Problem	Moderate Problem	Serious Problem
Difficulty Hearing (Loss of hearing)	☐ Either the symptom is not present or the symptom is present but does not cause difficulties	☐ The symptom causes some mild problems with day-to-day life, but these are manageable	☐ The symptom causes problems that have a moderate impact upon day-to-day life	☐ The symptom causes problems that have a serious impact upon day-to-day life

Therefore for the 'Difficulty Hearing' Question:

If the person you care for does not have any difficulty hearing, then tick the 'Not a Problem' box. Or, if s/he does have difficulty hearing but this does not cause any problems for her/ him (even if it is a bit worse), then tick the 'Not a Problem' box

If it causes some mild problems, but these are manageable, then tick the 'Mild Problem' box

If it causes problems that have a moderate impact upon their life, then tick the 'Moderate Problem' box

If it causes problems that have a serious impact upon their life, then tick the 'Serious Problem' box

Please tick ☑one box only

Carer – Head Injury Neurobehavioral Assessment Scale (C-HINAS)

Please answer all questions

During the past four weeks, to what extent have the following been a problem for the person you care for in her/his day-to-day life?

	Not a Problem	Mild Problem	Moderate Problem	Serious Problem
Temper / Irritable (Loss of temper, more aggressive, irritable, etc.)	☐	☐	☐	☐
Social behavior (Too loud, causing offence, acting childishly, saying the wrong thing, etc.)	☐	☐	☐	☐
Lack of motivation (Difficulty getting round to doing things, giving up too easily, etc.)	☐	☐	☐	☐
Difficulty with feeling tired/fatigued (Feeling tired, drained or exhausted, having less energy, etc.)	☐	☐	☐	☐
Difficulty with sleep (Sleeping a lot or not sleeping, having nightmares, etc.)	☐	☐	☐	☐
Feeling scared (Frightened, panic attacks, etc.)	☐	☐	☐	☐
Paranoia (Feeling more suspicious about people, etc.)	☐	☐	☐	☐
Feelings of loss (Troubled by loss of previous life or how life could have been, etc.)	☐	☐	☐	☐
Frustration (Because of not being able to do things you would like to, etc.)	☐	☐	☐	☐
Worrying about things (Feeling anxious or worried, etc.)	☐	☐	☐	☐
Crowds (Feeling uneasy in large crowds or amongst strangers, etc.)	☐	☐	☐	☐
Loss of confidence (Less confident in unfamiliar situations or when doing things you used to do, etc.)	☐	☐	☐	☐

Please answer all questions

During the past four weeks, to what extent have the following been a problem for the person you care for in her/his day-to-day life?

	Not a Problem	Mild Problem	Moderate Problem	Serious Problem
Depression (Feeling down or isolated, suicidal thoughts, etc.)	☐	☐	☐	☐
Arguments with close family (Arguments with partner, children, parents, etc.)	☐	☐	☐	☐
Reduced interest in family (Less loving, less caring, less affectionate, etc.)	☐	☐	☐	☐
Strain on family (Tension, stress or depression amongst family members, etc.)	☐	☐	☐	☐
Don't see friends as often as would Like	☐	☐	☐	☐
Lack of good friends (Close friends, etc.)	☐	☐	☐	☐
Lack of understanding from others (People don't understand their situation, people judge or label them, etc.)	☐	☐	☐	☐
Lack of people to talk to (Social interaction, people to confide in, etc.)	☐	☐	☐	☐

Carer – Head Injury Community Living Scale (C–HICLS)

Please answer all questions

During the past four weeks, to what extent have the following been a problem for the person you care for in her/his day-to-day life?

	Not a Problem	Mild Problem	Moderate Problem	Serious Problem
Difficulty with mobility (Getting around places, going up stairs, getting in and out of bed, etc.)	☐	☐	☐	☐
Lack of independence (Reliant upon help from others, unable to live by themselves, etc.)	☐	☐	☐	☐
Sports (Restrictions in playing sports, etc.)	☐	☐	☐	☐
Leisure activities (Restrictions in taking part in leisure activities eg, going to pub, cinema, going out for meals, etc.)	☐	☐	☐	☐
Preparing meals (Preparing / cooking meals, etc.)	☐	☐	☐	☐
Physical self-care (Washing, dressing, etc.)	☐	☐	☐	☐
Travel (Getting around local area, travelling to shops, visiting friends, going out, etc.)	☐	☐	☐	☐
Shopping (Buying food, clothes, things for everyday needs, etc.)	☐	☐	☐	☐
Local environment (Restriction due to steps or kerbs in local area, lack of ramps, handrails, etc.)	☐	☐	☐	☐
Difficulty with balance (Loss of balance, standing/sitting upright, walking, etc.)	☐	☐	☐	☐
Physical appearance (Changes to physical looks due to paralysis or scars, weight change, etc.)	☐	☐	☐	☐
Difficulty with eye-sight (Limited or blurred vision, can't see things properly, etc.)	☐	☐	☐	☐

Carer – Head Injury Cognitive Assessment Scale (C–HICAS)

Please answer all questions

During the past four weeks, to what extent have the following been a problem for the person you care for in her/his day-to-day life?

	Not a Problem	Mild Problem	Moderate Problem	Serious Problem
Group conversations (Difficulty following conversations when several people speak at the same time, etc.)	☐	☐	☐	☐
Difficulty reading (Difficulty reading letters, bills, newspapers, books, etc.)	☐	☐	☐	☐
Difficulty speaking (Words come out jumbled, they have to concentrate harder on speech, or people can't understand them properly, etc.)	☐	☐	☐	☐
Difficulty with recent memory (Forgetting things: eg, what day it is, what happened yesterday, etc.)	☐	☐	☐	☐
Difficulty with concentration (Focusing on reading newspapers, watching TV, doing tasks, easily distracted, etc.)	☐	☐	☐	☐
Difficulty with planning / Organisation (Doing things in the right order, allowing enough time, etc.)	☐	☐	☐	☐
Difficulty with multi-tasking (Doing more than one thing at a time: eg, walking and talking, etc.)	☐	☐	☐	☐
Dealing with money (Paying bills, knowing how much change they should get, etc.)	☐	☐	☐	☐
Safety risks (Leaving gas on, not safe crossing roads, using electrical goods, etc.)	☐	☐	☐	☐
Difficulty hearing (Loss of hearing, etc.)	☐	☐	☐	☐

Carer – Head Injury Physical Assessment Scale (C–HIPAS)

Please answer all questions

During the past four weeks, to what extent have the following been a problem for the person you care for in her/his day-to-day life?

	Not a Problem	Mild Problem	Moderate Problem	Serious Problem
Difficulty with headaches	☐	☐	☐	☐
Difficulty with pain other than headaches (Pain in body, legs, arms, etc. Not headaches)	☐	☐	☐	☐
Difficulty with Epilepsy / Fits (Blackouts, seizures, absences, etc.)	☐	☐	☐	☐
Difficulty with feeling dizzy / faint (Feeling as if head is spinning, vertigo, dizziness, feeling giddy, etc.)	☐	☐	☐	☐
Difficulty with buzzing noise in ear (Tinnitus, etc.)	☐	☐	☐	☐
Difficulty with sensitivity to noise / light (Can't tolerate noise or light, etc.)	☐	☐	☐	☐

How the injury has affected you:

The last few questions ask about how the consequences of the injury have affected you

During the past four weeks, to what extent have the following been a problem for you in your day-to-day life?

Effect on You	Not a Problem	Mild Problem	Moderate Problem	Serious Problem
Increased responsibility (Having to take decisions, dealing with finances, etc.)	☐	☐	☐	☐
Reduced social life (Not being able to go out as much or meet up with friends, etc.)	☐	☐	☐	☐
Feelings of loss (Of previous life, the way your life could have been, etc.)	☐	☐	☐	☐
Depression (Feeling down, etc.)	☐	☐	☐	☐
Feeling alone (Lack of support, etc.)	☐	☐	☐	☐
Less money (Lack of income, etc.)	☐	☐	☐	☐
Stress or strain	☐	☐	☐	☐

How the injury has affected you:

Were you working or studying before the person you care for had their brain injury?

Yes ☐ (please answer the question below)

No ☐ (please go to the next page)

During the past four weeks, to what extent has the following been a problem for you in your day-to-day life?

	Not a Problem for work	Mild Problem for work	Moderate Problem for work	Serious Problem for work
Work (Has caring for the person with a brain injury caused you problems with work / employment?)	☐	☐	☐	☐

Additional Comments

Thank you for taking the time to complete this questionnaire